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Review Article

Disease-Related Stigma, Stigmatizers, Causes, and Consequences: A Systematic Review

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Abstract

Background: Stigma is a sociological concept that is important in medicine and health because it threatens health as much as the disease itself. We aimed to explore the causes, stigmatizers, consequences and coping strategies related to the stigma of diseases by systematically analyzing relevant literature.

Methods: This systematic review examined 65 articles on Disease-Related Stigma by searching Noormags, Magiran, SID, Google Scholar, and PubMed databases. The articles were published in Persian and English between 2001 and 2022 and conducted in Iran. We used a three-step systematic review process to select articles that met the research criteria.

Results: Conflict in society, lack of knowledge, specific characteristics of the disease, and the contagious nature of disease are the main causes of stigma, leading to stigmatization by different groups such as significant others, generalized others, institutional others, and macro others. Patients experiencing stigma face various psychological, physical, and social complications, and they may use concealment as a coping strategy, which can pose a potential threat to society's general health.

Conclusion: By knowing the causes and stigmatizers of disease-related, it is possible to reduce stigma with less cost and time.

Keywords: Causes of stigma; Stigmatizers; Outcomes of the stigma

Introduction

Isolation of individuals with threatening characteristics is common trait in human societies throughout history (1). Goffman described these negative characteristics as stigma, which is a symbol with negative connotations that reduces a person's identity to a contaminated state, leading to undervaluation and marking them as a symbol of deviation (2). Stigma marks a deviation from the natural phenomena of society and is a sociocultural process in which marginalized groups are recognized as undesirable.

This concept was used in the 18th century to refer to the unfavorable characteristics under which various diseases existed (3). In such a way that during outbreaks of plague, tuberculosis, cholera, and yellow fever, the infected were isolated, and movement of these people was supervised (1). Diseases are not inherently stigmatizing, but society's stereotypes of them can create stigma. Ste-

reotyping, labeling differences, and assigning people to particular groups are the beginning of the stigmatization process (3, 4). Negative stereotypes such as fear of infection (5), danger, unpredictability, violent (3, 6), greediness, laziness, dirtiness, and smelliness (3, 7), the association of the disease with death and obscene behaviors such as homosexuality, drug use, sex work, or the way it is transmitted through sexual intercourse, considered taboo in some cultures (5), the occurrence of antisocial behaviors (7) and also the existence of a common mental agreement regarding the negativity of diseases (8), leads to stigma. Therefore, some diseases are classified as unpleasant and threatening pains and considered harmful.

Stigma is described by the WHO (9) as a "hidden burden of disease," which has psychological, physical, and social consequences (10). In addition to directly impacting mental health (11), it can lead to separation, exclusion, reduction of interaction (12, 13), and depriving people of equal opportunities. It also causes the erosion of social support by losing supports from their network of relationships (3) and hinders medical care, including seeking, starting, and continuing treatment.

Stigma reduces trust in doctors (14), and less confidence causes less attention to doctor's advice and lack of follow-up and adherence to the care (14-17). Basically, by ignoring the treatment steps and postponing it, the patients have to protect themselves from facing the label and stigma and at the same time and create challenges in managing the disease and following the medical and treatment instructions (1, 11). Stigma is an influential factor in preventing treatment in 40% of patients with mental illness (5). Some people turn to non-specialists instead of going to a specialist doctor, faced with no change in their disease status or worsening of their disease (18). On the other hand, stigma causes inequality in the access of care services such as medical insurance to the patient and hinders the enjoyment of health services (1, 6). Inequality in providing services (19) also causes a decrease in the individual's health; These two consequences, in combination with each other, cause a reduction in the general health of society. Therefore, stigma can threaten patients' health to the extent of the disease itself and the pains caused by it (11).

Because of the importance of this concept for individuals and social health, various empirical studies on disease-related stigma have been conducted all the world in recent decades; these studies were conducted on patients suffering from multiple diseases, such as mental illnesses (20), AIDS(21), leprosy(22), cancer(23), autism(24), Down's syndrome(25), diabetes(26), obesity(27), intestinal disorders (28), epilepsy(29), and recently coronavirus(30). The research done in Iran on the concept of stigma is mostly in the medical field and has been done on various diseases (31-34), which shows the importance of this sociological concept in medical issues. However, despite extensive empirical studies, few systematic reviews have been conducted in this field; A systematic study which focused on different stigmatized groups and did not specifically focus on the stigmatization of patients. Other studies, like Heydari et al. (2013), Mohammadi et al. (2012), and Iraqi Mejard et al. (2021), also focused on only one group of patients who did not have different types. Moreover, the disease-related stigma is more evident in developing countries (35).

Therefore, with this realization, we intend to systematically review the literature related to different diseases-related stigma in Iran and address these questions; What causes disease-related stigma? Who is the stigmatizer? What are the consequences related to disease-related stigma? What ways do patients use to cope with stigma? Ultimately, we will discuss this issue from a sociological perspective.

Methods

Using a systematic review, quantitative and qualitative studies were examined simultaneously to provide a comprehensive understanding. The systematic review protocol consists of three steps: identifying keywords, selecting and reviewing criteria, and entering articles into research (36).

Search Criteria

We limited the initial search to articles published in Persian and English from 2001 to 2022. The researcher conducted the search strategy from 10 May 2022 to 20 May 2022. By identifying the databases, a search strategy was conducted in national and international databases such as Noormags, Magiran, SID, Google Scholar, and PubMed. By studying the literature, keywords were identified for the search. The keywords stigma, disease-related stigma, labels, social stigma, social labels, the stigma of Iranians, stigma in Iran, the stigma of health, and stigma of disease are utilized in the literature review. The initial search was done using only one keyword; Due to the lack of access to all articles, researchers used 'OR' and 'AND' to link synonyms and categories. This process followed helped to identify the articles.

Eligibility criteria

Bias in systematic review studies can be reduced as much as possible by using the appropriate search strategy (37). Therefore, in the present study, when determining the inclusion and exclusion criteria to address potential bias in the design of the study review and for quality assurance, some requirements of the PICOS approach were used (38) (population, intervention, comparison, outcome, study type). In addition, three researchers searched for articles at the same time.

- **Population**: Patients who experienced/perceived stigma.
- **Outcomes of interest**: The causes of disease-related stigma, stigmatizer, consequences of disease-related stigma, and The ways to cope with stigma.
- **Study design**: Any qualitative or quantitative study reported in Persian or English and done in Iran.

Inclusion criteria: all the scientific articles related to the stigma of disease conducted in Iran, published in Persian and English languages, and scientific journals that the statistical population was patients, and their results were aimed to address the research questions selected for initial review. Letters to the editor, articles without access to the full text, articles conducted on Iranians abroad, and articles without relevance to the topic were excluded.

Study selection

The title and abstract of the articles were evaluated independently. Studies with Eligible criteria were received in full and saved in Endnote version 20.2.1, and repetitive references were deleted. Then, all the articles were analyzed, and the titles and abstracts were carefully checked to determine their eligibility. Two reviewers reviewed each article to ensure compliance with inclusion criteria and the accuracy of extracted data.

Study characteristics

After the initial search, 426 articles were identified and included in the review. Ninety-seven articles indexed in two or more databases were removed from the list. The papers were reviewed based on their titles, and 117 articles were excluded from the disease-related stigma field. After these two stages, 212 articles remained whose titles and abstracts were studied, and 88 articles that were not conducted on patients or their families or were studied on Iranians abroad were removed. The remaining 124 papers were thoroughly examined; 59 were removed owing to a lack of analysis of the concept's dimensions. Finally, 65 articles dealing with the disease's stigma remained for review (Fig. 1).

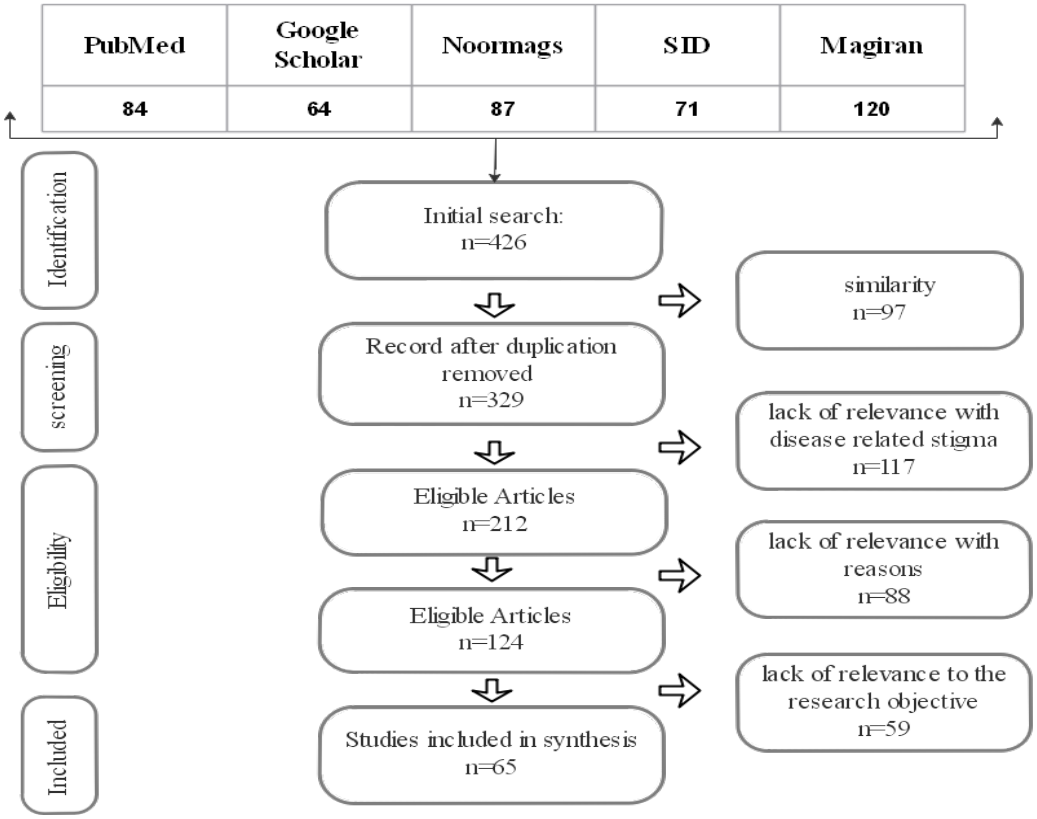

Fig. 1: Flow diagram of selection of articles, based on PRISM guidelines, 2021

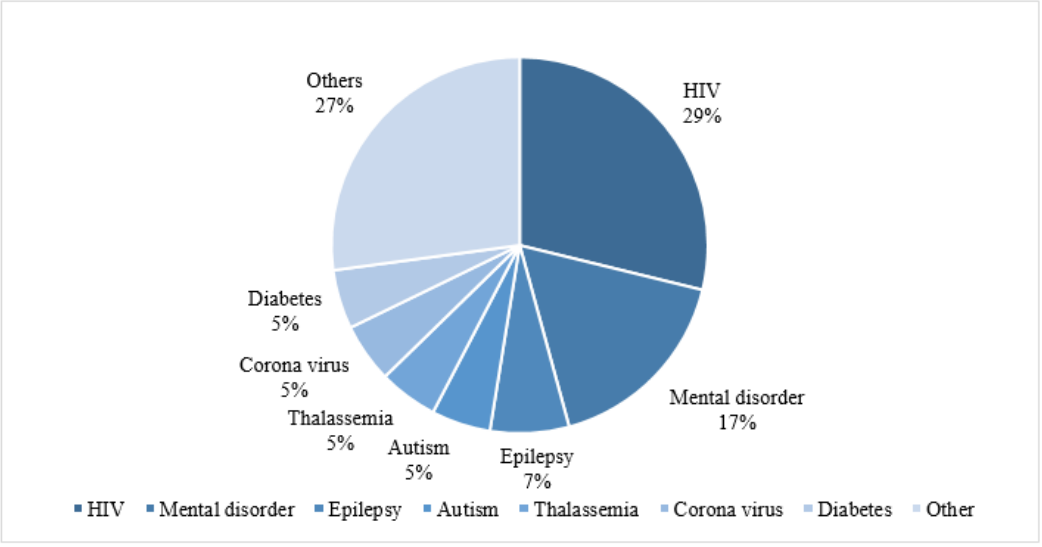

Fig. 2: Frequency of diseases

Figure 2 shows the general view of the studies. HIV disease, mental disorders, and epilepsy had the most frequent among the studies. The others item include Obesity, Physical disability, Alzheimer, Cancer, Infertility, etc., with less than 3 Frequency.

Results

The results of the research are described in four categories: "Causes of disease-related stigma, " Stigmatizer," " Consequences of stigma," and " The ways to cope with it. "

The causes of disease-related stigma (Table 1), can be categorized into four categories: value conflict in society, lack of awareness, specific disease characteristics, and disease prevention. Noncompliance with social values is the main cause of stigma, and other causes follow in a particular order. Therefore, the importance of the role of macro structures of society in stigma is clarified (8, 39, 40).

Table 1: Causes of stigma

The causes of disease-related stigma	*Semantic unit*	*Type of Disease*	*Frequency*	*Percentage*
Value conflict	The disease's nonconformity with the social structure, Conventional norms, and the society's cultural and traditional roots/ Negative attitude/ Unpopularity, as well as traditional disease beliefs	Premature baby/AIDS/Gender identity disorder/Down syndrome/Schizophrenia/ Cancer/Corona Mental disorder/Hepatitis	23	52/3
Lack of awareness	Regarding the mode of the transmission/ Regarding the disease itself and its unknown nature	Neurofibromatosis/ AIDS/ Thalassemia/ Mental disorder/ Alzheimer's/ Diabetes	11	25/0
Specific characteristics of the disease	The special way of transmitting the disease and its connection with immorality/ Rhe patient's inability to do things/ Rhe prolongation of the disease	AIDS/mental disorder	6	13/6
Disease prevention	Fear of getting sick	AIDS/liver cirrhosis	4	9/1

Stigmatization can be caused by exploitation, value conflict, or fear of disease spread (39, 41, 42). The main reason in this study is value conflict. In Iran, the value of health creates stigmatization towards the sick as deviant, weak, and useless individuals (41-43). Because of traditional attitudes about worthless, some diseases make people identify as weak and useless (44, 45). The perception of fear and avoidance of disease also causes stigma (46-48). When the existence of difference causes vulnerability or the possibility of death, a kind of existential anxiety is formed in the person, leading them to avoid those who are different (39). However, in many cases, the root cause of this behavior is lack of awareness (31, 42, 49-51) about the disease and its unknown nature (51, 52) or about the way the disease is transmitted (49, 53, 54).

Stigmatizers. Table 2 summarizes the people how stigmatized. These people can be divided into four categories; the *important other* includes family, relatives, friends, and others; the *generalized other* includes strangers and community members; the *institutional other* such as the healthcare service providers such as physicians, nurses, etc., and the *macro other* like the media.

Table 2: People how stigmatized

Stigmatizers	*Semantic unit*	*Frequency*	*Percentage*
The Significant Other	Family, relatives, friends	35	50/0
The Generalized Other	Strangers and community members	15	21/4
The Institutional Other	Healthcare service providers	13	18/6
The Macro Other	Media	7	10/0

The family and relatives of a patient are a common source of stigma that can lead to a lack of family support, despite having a close relationship with the patient (44). If family stigma is combined with mistreatment by society, low self-esteem, and a lack of religious beliefs, it can lead to more perceived stigma.(21, 55). The institutional other includes healthcare workers who have a special role in the production and reproduction of stigma (56). Physicians and nurses, who are aware of the disease, participate in directing stigma and stereotyped behaviors (57) along with those in power (45). The generalized other is a stigmatizer that considers a stranger's social identity characteristics, which can lead to stigma if they are displeasing. Obvious characteristics result in faster stigma. The macro other such as the media, as a primary source of information, plays a significant role in shaping society's perception of a situation situat(58). It often promotes stigma and societal misperceptions on radio and television (59).

Consequences of disease-related stigma Stigma has psychological, physical, and social health consequences; such as shame, blame, and humiliation (mental health); exclusion, discrimination, and loss of opportunity (social health); and refraining from treatment, which can lead to disease aggravation (physical health).

Table 3: Consequences of disease-related stigma

Consequences	*Semantic unit*	*Frequency*	*Percentage*
Psychological health	Shame /Blame /Humiliation/ Fear of loneliness and judgment/ Decreased self-esteem/ Desire for death/Feeling worthless and discredited/Despair/Embarrassment/ hope/ Uselessness/Ridicule / Depression/ Incompetence/ Anxiety/ Stress/ Dependence/ Disgrace/ Anger/ Frustration/ Feeling of guilt / Feeling of loneliness/ Feeling of ugliness/ Suicide attempt/ Mental illness/ Negative self-attitude/ Worry about the future/ Impact on mental health/ Feeling of misery/ Decrease life satisfaction/ Body dissatisfaction	101	52/39
Physical health	Refusal to go to the treatment center/ Delay in seeking treatment and exacerbation of the disease/ Failure to follow-up treatment	9	4/7
Social health	Rejection/ Discrimination/ Defamation of identity/ Lack of respect/ Refusal to marry/ Loss of job/ Self-inflicted isolation/ Disruption of family relations (divorce, breakup)/ Abusive behavior/ Erosion of social network/ Degradation of base/ Exclusion from social participation/Loss of social support/Being oppressed by others	81	42/4

As described in Table 3, Stigma's social health effects include exclusion and discrimination from social life. There are two types of social exclusion: interactional and opportunity. Interactional

exclusion is mostly by family and kinship networks (60), but other groups like doctors also do it(53, 56, 60-64). Opportunity exclusion includes various economic-social opportunities and not being able to participate in society (53, 56, 60-64). Stigma can affects physical health; Patients avoid treatment or do not follow the treatment process or stop taking medicine to prevent others from knowing, leading to worsening disease and physical health consequences (6, 65). Stigma causes psychological and social stress, leading to negative attitudes, feelings of invalidity, shame, and worthlessness. These effects harm mental health and persist as long as patients perceive themselves as inferior to society's standards(6, 10).

The ways to cope with stigma

Stigma causes a gap between social and real identity, resulting in negative consequences, So People use various ways to manage their identity. Because stigma is an obstacle to accessing human right, patients and their families often conceal their disease to avoid stigma, labeling (41, 51, 66-68) and prevent losing social status and emotional ties, as well as experiencing social exclusion and inappropriate interactions (42, 53, 62, 69, 70). This strategy, in the case of contagious diseases, leads to endangering the health of society (21, 42). However, Some patients, called "saving victims" (62), reveal their illness to reduce the risk of the rest of society getting infected, while others passively surrender and avoid any reaction due to fear of social exclusion. The latter strategy can lead to more isolation and exclusion (71).

Discussion

Stigma is a social concept that due to its nature has penetrated the medical area. It is used for various illnesses and diseases. This article reviews 65 studies on disease-related stigma and identifies causes, stigmatizers, consequences and coping strategies. Lack of knowledge, disease characteristics, contagious of the disease and preventing from contracting it, are the main reasons for stigma by significant other, generalized other, institutional other, and macro other. Patients face psychological, physical, and social consequences and cope with stigma through concealment strategies.

The causes of disease-related stigma

Stigma is a prevalent issue in societies that can be caused by negative stereotypes and attitudes towards those who deviate from cultural norms (4) and when negative stereotypes are endorsed, it results in stigma (72). In Iran, the culture of perfectionism leads to stigmatization of those who don't conform (73). Certain disorders like AIDS can be stigmatized due to risk of transmitting the virus to others (42, 48, 66, 74) and the way people become infected that is attributed to sexual deviations (43, 54). Other disorders, such as cancer due to its association with death (61) and mental disorders due to inappropriate behaviors, can also be stigmatized (31, 75).

Stigmatizers

Stigma consists of three basic stages: label, response and consequence. In the first stage, which is labeling (76), patients are stigmatized by four main groups, including family, physicians, the generalized public, and the media. Family may view patients as criminals (77), causing patients to distance themselves and hide their condition, and experience negative reactions such as pity (66, 78, 79). Physicians are known to discriminate against patients. A survey in 2000 by the Columbia University Mental Health Foundation, found that 44% of mentally ill adults had experienced discriminatory treatment from their doctors. Therefore, doctors with label, neglect and adopt avoidance actions towards patients, worsen the crisis for the patient and their family (80), such as hand beating, avoiding the hand beating, ignoring the patient's request and not visiting (56, 81). Generally, support organizations and physicians can decrease trust in the doctor and their recommendations and create a platform for mistrust (14). The generalized other as third group, stigmatizes through avoidance (80, 81), blame (82), ridicule (83), discrimination (84) and even encourage others to avoid patients (79). Lastly, media's symbol-

ic actions contribute to stigma by portraying individuals who deviate from societal norms (85) and gives a legal aspect to stigma (86). Media as a structural power, establishing negative attitudes to patients through unrealistic representation (87).

Consequences of stigma

Stigma has negative consequences in social, psychological, and physical dimensions. In the social domine, not providing medical services to patients by physicians (48), discrimination in terms of public services (42, 49, 53, 75, 83), and cause patients to hide their disease (48, 49, 53, 56, 63), creates a fear of being judged by others (88, 89) and prevent healthy behaviors and social adaptation (88). Stigma can harm physical health by discouraging healthy behaviors, access to healthcare, medicine, and treatment adherence. Stigma also exacerbates health problems, disease control, and transmission (1). Physicians' stigmatization can lead to non-follow-up and decreased health levels (5, 16). Stigma has severe psychological consequences such as blame (41, 62, 71, 87, 90), guilt (21, 41, 91), depression (53, 63, 83, 91-93), low self-esteem (41, 94-97), and humiliation (56, 67, 83, 87, 93), leading to mental health disorders, social isolation, low quality of life, and violent behaviors like suicide (32, 49, 56, 74, 83, 93, 97, 98). Stigma can also affect the patient's family and cause them to experience shame (32, 64, 91, 92, 99).

Limitations

The study did not face specific limitations, but its results should be carefully applied to other diseases since most research focused on mental disorders among HIV and AIDS patients

Conclusion

Stigma arises from negative labels and stereotypes during social interaction and becomes a structural element that affects people's behavior towards those possessing certain traits, including those with diseases. Stigmatizing patients can lead to exclusion from citizenship rights, social interactions, and socio-economic opportunities, worsening their health outcomes and causing a hidden gap of inequalit. Patients may hide their illnesses, which poses a risk to society. Programs to stop the stigma and raise awareness should be implemented to make society safer and healthier. Stigma is a social constructionism, not a pre-existing reality that cannot be addressed through awareness programs and attitude change. Instead of reacting negatively, positive and negative dualities in society should be accepted. By stigmatizing, we not only fail to avoid danger but also make the situation complex and potentially endanger the general society. Awareness programs can regulate people's behavior without stigmatizing patients. In addition, doctors can create a foundation for attitude change by changing their own attitudes and behavior.

The systematic review provides suggestions for future research on stigmatization. Studies should focus on identifying groups that impose stigma and their negative attitudes, perceptions, and reasons for stigmatization. Identifying the needs of stigmatized patients and available resources can help in controlling their problems and preventing the spread of stigma. Research on patients with diseases like leprosy, cancer, and obesity is necessary, along with focusing on strategies for identity management. Future research should also provide intervention solutions and programs to reduce stigma at the structural and media levels, as well as by doctors.

Journalism Ethical considerations

Ethical issues (Including plagiarism, Informed Consent, misconduct, data fabrication and falsification, double publication and/or submission, redundancy, etc.) have been completely observed by the authors.

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Conflict of interest

The author declares that there is no conflict of interest.

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